



The Asthma Caregivers and Children Study

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Executive Summary

Preventing asthma exacerbations is a key asthma care goal for children with asthma. Exacerbations happen when a child has so much trouble breathing that they need urgent care or emergency room treatment. The risk of having an exacerbation can be reduced by avoiding things that “trigger” breathing problems, using “quick relief” or “rescue” medication to relieve acute breathing problems, and using daily medication for persistent asthma subtypes. However, these actions are more challenging in areas with higher poverty rates, limited access to medical resources, unmaintained housing, and inadequate environmental protections.

The Asthma Caregivers and Children Study sought to understand how families’ social situations influence their understanding of asthma and their understanding of their child’s risk of having an exacerbation. It also examined how these understandings influenced the ways that families managed asthma.

This report is based on what we learned from three groups of people in St. Louis, Missouri and Gainesville, Florida:

- caregivers of a child with asthma,
- healthcare providers who provide asthma care, and
- children with asthma and their siblings.

We interviewed 41 caregivers and 12 health providers. We also made home visits or online interviews with 25 children. Most caregivers and children were Black and/or had low incomes. Health providers included pediatricians, school nurses, pulmonologists (doctors who specialize in lung diseases), an asthma coach and an emergency room physician.

Key Findings

The most important findings from our research include:

1. Challenges with housing influenced how families managed asthma.

Caregivers and children managed asthma while dealing with many difficult situations related to housing. For example, landlords who didn't maintain their housing made it hard for children to avoid mold and pests. Some children needed to move between different households and family members, which made managing triggers and medication difficult. However, many caregivers and children had help managing asthma from siblings, family members, and school nurses.

2. Caregivers often understood their child's asthma by comparing it to other people's asthma.

These comparisons influenced caregiver's thoughts, feelings, and decisions about their child's asthma care. For example, comparisons sometimes helped caregivers evaluate the seriousness of their child's asthma and determine whether they needed treatment for symptoms.

3. Children's asthma was often undertreated.

Caregivers and children were disconnected from the healthcare system due to challenges that were outside of their control. For example, caregivers lost trust in healthcare providers when they felt unheard or when they perceived that their children were not receiving adequate treatment. In addition, transportation difficulties and a shortage of primary care providers made it hard for caregivers to take their child to the doctor. Caregivers and children often turned to home remedies to avoid asthma triggers and reduce symptoms.

4. Caregivers and children used their bodies to understand asthma.

They also used their bodies to understand how asthma felt and how it could be best treated.

Caregivers and children experienced asthma at the same time that they felt other sensations in their body. This made it hard to tell asthma apart from conditions like anxiety, panic, allergies, or the common cold. In addition, the temporary severe symptoms of asthma were more noticeable than the long-lasting lung inflammation. This led caregivers and children to believe that asthma was a temporary problem that was only present when symptoms were exacerbated.

5. Healthcare providers, caregivers, and children could all have different views of what managing asthma can and should involve.

Healthcare providers often viewed asthma as a biological illness that required medical tests and treatments. Caregivers focused mostly on preventing or treating symptoms by trying to remove asthma triggers from the home, managing children's emotions, and using medicine or other home remedies. Children focused mostly on treating asthma symptoms that come on suddenly.

6. Children were important in managing asthma and did many tasks to care for their asthma.

For example, they often were in charge of remembering to take daily controller medication and deciding when to take their quick relief medication. Sometimes friends or siblings helped children with asthma. However, adults did not always see or recognize these tasks, so children's work was not often understood or supported.



7. Children's asthma management strategies were often shaped by challenges outside of their control.

Challenges like school policies that limited access to inhalers, children's complicated feelings around asthma medications, and distance between children and their medication were barriers to children's asthma management. Children often used water to help their asthma because it was more accessible than other options.

Key Messages and Recommendations

This report is intended for multiple audiences including primary care physicians and other healthcare providers, members of asthma advocacy organizations, caregivers of children with asthma, and other stakeholders. Below are key messages and recommendations from our research:

- Advocates for families of a child with asthma need to consider asthma management holistically and elevate the housing needs and social contexts of families.
- Children play central roles in their asthma management, and caregivers and healthcare providers should make efforts to actively recognize and include them in their asthma care.
- Caregivers' and children's understandings of asthma are richer than purely biomedical approaches, and healthcare providers need to respect these in order to maximize the quality of asthma care.

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Background

Childhood asthma affects over 5 million U.S. children (1). However, asthma is more common among children who are Black and whose parents have limited incomes and formal education (2). This difference in asthma rates is due to many factors that are not under the control of caregivers or children. For example, discriminatory housing practices result in racially segregated neighborhoods with more asthma triggers (3,4). In addition, discriminatory or weak environmental laws can result in people in Black neighborhoods living closer to highways and chemical plants than people in white neighborhoods (5). This means that Black families are exposed to more air pollution and toxins that harm children's lungs (6). There are also fewer healthcare providers in Black neighborhoods than white neighborhoods (7). This means that Black families have to travel farther to get healthcare.

Preventing asthma exacerbations is a crucial asthma care goal for children with asthma. An asthma exacerbation happens when a child has so much trouble breathing that their normal medicine does not help them get completely better (8). A child who has an exacerbation may have to go to urgent care or the emergency room for treatment. Because asthma exacerbations can be life-threatening, our research has focused on how caregivers, children, and doctors and other healthcare providers understand and manage asthma.



In the United States, asthma treatment focuses on self-management. Self-management means that, in theory, doctors would give the tools and training for asthma care to patients and caregivers and offer them support (9). At the time of this study, asthma self-management primarily included children self-monitoring with peak flow meters or using medications like inhaled corticosteroids that children with asthma take every day for long periods of time (10). These medications are meant for persistent asthma subtypes. For this reason, they are often called “controller” or “preventer” medications. Self-management also often included short-term “quick relief” or “rescue” inhalers like albuterol. These medications are meant to relieve acute breathing problems that happen suddenly.

Close relationships between doctors and patients or caregivers are important for making sure self-management works as intended. However, in the U.S., high healthcare costs, long distances to healthcare providers, and inadequate insurance coverage make it challenging for people to have close relationships with doctors (11,12). Families who are Black or who have low incomes have an especially hard time accessing adequate asthma care, because they are more likely to experience these challenges than families who are white or have higher incomes (13).

Purpose

Our long-term goal is to create tools to help families care for their child with asthma. However, there is little scientific information about how families’ social situations influence their understanding of asthma risk and their asthma management practices. For this research project, we studied how caregivers understand and manage their child’s asthma. This involved finding out how caregivers’ thoughts, decisions, and social situations influenced their ideas about asthma risk and the ways they managed asthma. We also wanted to see how children and doctors and other healthcare providers treated asthma. We were especially interested in how asthma care differed among families, households, and communities.

Study Location

We completed this research in two communities: Gainesville, Florida and St. Louis, Missouri. Residents in both St. Louis and Gainesville experience racism, poverty, and environmental injustices that shape asthma trends. Both cities are segregated so that the Black populations in North St. Louis and East Gainesville experience higher levels of poor housing conditions, stress, and environmental risks for asthma like air pollution (14,15).

These areas also have limited access to supermarkets, pharmacies, public transportation, and healthcare facilities. Between 2010-2015, rates of asthma-related emergency room visits were 8.5 times higher for Black residents than White residents in St. Louis (16). In Alachua county (where Gainesville is located), emergency department visits for asthma were six times higher for Black than for White residents in 2018 (17).



St. Louis, Missouri



Gainesville, Florida

Methods

Caregiver Interviews

Caregivers were recruited to participate in 60-minute interviews between December 2018 and May 2019 in St. Louis, MO and Gainesville, FL.

To recruit participants, we called community members who were registered in each universities' recruitment database. We also posted to social media and placed flyers at public locations like laundromats, urgent care centers, and doctor's offices.

Caregivers could participate if they were age 18 years or older, cared for a child under 18 years old with asthma, and spoke English. Several months into the study we discovered that few participants had low incomes or cared for a child with severe asthma. We increased our recruitment efforts for these people to make sure their voices were heard, too.

Two interviewers from each city completed each of the 41 interviews, with 25 interviews in St. Louis and 16 in Gainesville. Caregivers received a \$50 gift card for their time.

We asked caregivers questions about asthma treatment, asthma problems their child experienced, how they managed their child's asthma, and the effects of asthma on everyday life.

Interviews with doctors and other healthcare providers

We recruited healthcare providers (i.e., doctors and other healthcare providers) through university and professional networks. We interviewed these healthcare providers by phone or in person for about an hour. Participants were offered a \$50 gift card or check for their time.

Interviewers asked these healthcare providers what they thought were the main problems for caregivers, children, and families. They also discussed solutions to these problems.

Healthcare providers were asked about how they understood asthma, how they thought caregivers and children understood asthma, and what roles healthcare providers, caregivers and children had in managing asthma.

[Household visits and online interviews with children](#)

We used a child-centered approach in our household visits. This means we saw children as unique individuals who are able to meaningfully participate in their own asthma care and research. Because children's asthma is managed mainly in the home, we also used household visits.

Our original goal was to visit 12 families in their homes. We would visit them twice within a three-month period. Before the COVID-19 pandemic began, we made the first visit to the homes of 9 families. In those 9 families, there were 14 children with asthma and 6 siblings. After the pandemic hit, we moved the study online. We did online follow-up interviews on Zoom with 6 children. We also finished 9 online interviews with 5 newly recruited children.



Participants

Caregivers

We interviewed 41 caregivers: 25 in St. Louis and 16 in Gainesville. Most were women (83%), Black (80%), and/or had low incomes (78%).



Doctors and other healthcare providers

We interviewed 12 healthcare providers: 7 in St. Louis and 5 in Gainesville. This included pediatricians, school nurses, pulmonologists, an asthma coach and an emergency room resident.



Children

We held household visits and online interviews with 24 children: 10 in St. Louis and 14 in Gainesville. Most children were between the ages of 6 and 16 and had mild to moderate well-controlled asthma. The majority of children were Black (71%) and boys (58%).



Due to recruitment challenges in St. Louis, we did most of the online interviews with children in Florida. Families received a \$50 gift card for their time.

During household visits, we used activities like drawing, photography, and interviews to learn about children's experiences with asthma. Household visits averaged around 1.5 hours in length.

For the Zoom interviews, we delivered a "goody bag" full of snacks, craft supplies, and play materials before each interview along with a research iPad and portable wifi device. Before children logged on to Zoom to complete the interview, they and their caregiver filled out an online consent form. The Zoom interviews could involve story-telling and interactive drawing activities through the Zoom "whiteboard" feature. Online interviews with children averaged around 45 minutes each.

Analysis

We audio recorded all interviews with all participants. Then, a company transcribed the recordings.

We started analyzing the data by reading a small number of transcripts and notes. Then, based on that reading, we identified themes that came up in the interviews. For each transcript, we labeled parts of the text that fit each code and theme. After the transcripts were labeled with codes and themes, we summarized what we saw. The research team held regular meetings to discuss how our personal experiences with caregiving, asthma, and structural advantages and disadvantages shaped our thoughts about what the participants said.

Table. Characteristics of Caregivers (N = 41)

Caregiver Characteristics	N (%)
Site	
Gainesville, FL	16 (39%)
St. Louis, MO	25 (61%)
Gender	
Woman	34 (83%)
Man	7 (17%)
Age	
18-25	2 (5%)
26-30	2 (5%)
31-35	10 (24%)
36-40	6 (15%)
41-45	11 (27%)
46-50	8 (20%)
50≤	2 (5%)
Racial background*	
Black/African American	30 (67%)
White	11 (24%)
Asian	1 (2%)
American Indian/Alaska Native	3 (7%)
Financial status†	
Low	32 (78%)
Medium or higher	9 (22%)
Insurance	
Private-Employer paid	7 (17%)
Private-Marketplace	2 (5%)
Medicaid	29 (70%)
No insurance	1 (2%)
Did not report	1 (2%)
Education	
Graduate, professional, or bachelor's degree	11 (27%)
Associate's degree or vocational/technical school	11 (27%)
High school degree or equivalent	14 (34%)
Less than high school	5 (12%)
Relationship to child	
Parent	39 (95%)
Grandparent	2 (5%)
Household Characteristics	
Total household occupants	
2-3	13 (32%)
4-6	23 (56%)
7 or more	5 (12%)

Table. Characteristics of Caregivers (N = 41)

Households	N (%)
Number of adults in household	
1	17 (42%)
2	14 (34%)
3 or more	10 (24%)
Age of child with asthma †	
0-4	9 (22%)
5-11	24 (59%)
12-17	18 (44%)

* Some participants identified with more than one racial category. One caregiver (2%) also identified as Hispanic ethnicity.

† Participants were considered having low incomes if they reported not being able to pay an unexpected \$500 medical bill not covered by insurance or answered that the statement “I really can’t make ends meet” best described their financial status.

‡ Calculated as percentage of households reporting at least one child with asthma in a given age bracket. 16 families (39%) included more than one child with asthma.

Findings

1. Challenges with housing influenced how families managed asthma.

Caregiver interviews strongly indicated the importance of understanding asthma care in the context of issues like residential segregation, poverty, air pollution, and governmental disinvestment in communities of color. These issues influenced asthma risk, access to asthma care, and families' living situations. They also led to housing conditions, family structures, and health disparities that shaped how families managed asthma at home.

Many caregivers and their families lived in housing conditions that made asthma worse

Events like housefires caused loss of asthma medications or nebulizers and caused trauma and disruption for families. Caregivers who lived in older housing and who had landlords who refused to fix problems also struggled with mold, dust, flaking paint, holes in the walls, pests, and other problems.



Families cared for asthma across several households. This often made medical care more complicated

Caregivers and their families lived in different houses with different family members. In addition, families in which the parents were separated, or when the grandparents cared for the child after school meant that children were cared for across multiple households. This made caregivers worried about whether other caregivers would know how to care for their child's asthma. They also worried when other caregivers held different views and experiences of asthma.

Families dealt with multiple medical issues in the home at the same time. This meant asthma was not always a high priority

Most caregivers said that there was at least one other health problem affecting the child with asthma or another household member. These problems included autism, ADHD, complications from prematurity, Crohn's disease, sickle-cell, hydrocephaly, COPD, heart disease, dementia, and cancer. Caregivers managed these health issues in the context of other social issues like family violence, incarceration, sexual assault, and caregivers' own physical and mental health issues. These other health and social issues made it hard for caregivers to prioritize their child's asthma.



2. People understand and make decisions about their child's asthma based on comparisons to other people.

Asthma can be a complex and confusing disease. Caregivers gained an understanding of their child's asthma by comparing their child with other people who have asthma. For example, they compared their child with other children with asthma, other family members, or the caregivers themselves if they had asthma. These comparisons may be an underappreciated source of information that caregivers use to understand their child's asthma and to make treatment decisions.

Influence on thinking

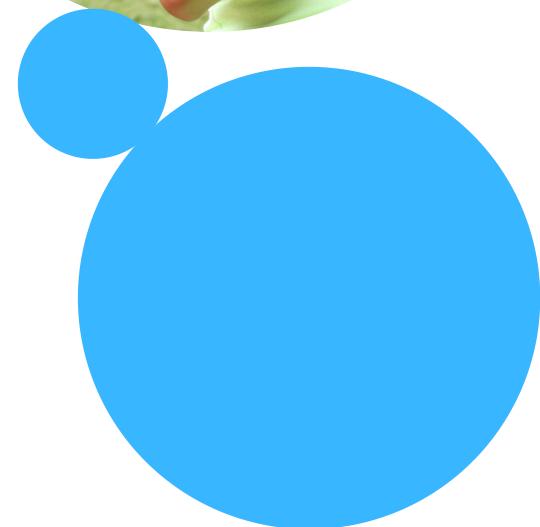
Comparisons helped caregivers recognize that their child had asthma, distinguish asthma from other breathing problems, and determine the seriousness of their child's asthma.

Influence on feelings

Comparisons influenced how caregivers felt about their child's asthma.

Comparing their child with others who had asthma inspired positive feelings such as gratitude when caregivers concluded that their child's asthma was not as bad as the asthma of others.

Caregivers also felt hope when the comparisons suggested a possible positive future for their child. The comparisons could also cause caregivers to worry over how bad their child's asthma could become and frustration if caregivers' positive expectations were not met.



Influence on decisions

Comparisons influenced how caregivers managed their child's asthma. Sometimes, this resulted in decisions that were different than how doctors and other healthcare providers cared for asthma. Sometimes caregivers used comparisons to motivate their child's asthma management practices.

3. Children's asthma was often undertreated.

Many of the children in our study had not received sufficient medical treatment for their asthma. Doctors and other healthcare providers noted that the undertreated asthma occurred because families didn't always remember to give children controller medication, didn't understand the importance of controller medication, or needed controller medication but were not prescribed one. From our interviews with caregivers, doctors, and other healthcare providers we found three types of disconnects that helped explain why children's asthma was undertreated:

Interpersonal disconnects

Interpersonal disconnects included different views about asthma and asthma management between caregivers and providers as well as caregiver mistrust in healthcare providers. These differences resulted in misunderstandings and under-prescription of controller medications for childrens' asthma.

Resource disconnects

Resource disconnects included a lack of healthcare providers in disadvantaged areas, challenges to accessing primary care due to time and transportation constraints, and caregivers' prioritization of severe issues during short appointments with primary care physicians. Caregivers also experienced life disruptions due to other illnesses and issues, which limited their time and ability to care for asthma. Providers had limited access to educational resources about children's asthma, which impeded their care.

System disconnects

System disconnects included difficulties with insurance, primary care shortages, gaps between emergency and primary care, urgent care replacing primary care, institutional racism, and physician under-prescribing. This led to situations where caregivers had difficulty following up with primary care physicians after taking their child to urgent care, and providers faced challenges communicating to each other across different healthcare systems.

We ultimately found that children's asthma was undertreated because caregivers had a hard time accessing professional medical care. Part of the reason for difficulties accessing care was because the interpersonal, resource, and system disconnects described above resulted in distant, strained, or intermittent relationships between families and healthcare providers. This "disarticulated care" left caregivers without the training or resources to manage their child's asthma on their own



4. Caregivers and children used their bodies to understand asthma.

Doctors understood asthma to be a chronic illness with symptoms that were always present, even if they couldn't be felt. Doctors and healthcare providers described trying to convince caregivers that their child was chronically ill with asthma by using stethoscopes, spirometers, or Asthma Control Tests (ACTs).

However, caregivers and children used their body to understand asthma as an acute disease with symptoms that were confusing and that came on suddenly.

Caregivers and children experienced asthma at the same time as other sensations happening in their bodies

Asthma symptoms like breathlessness, wheezing, and cough could feel or look similar to signs of other illnesses. Caregivers often described challenges with telling asthma symptoms apart from other health issues like anxiety, allergies, obesity, stress, or colds.

Children also linked asthma to a range of symptoms, including vomiting, sore throat, nasal congestion, and heart pain. Because asthma symptoms were ambiguous, children and caregivers reported using inhalers to improve breathing difficulties like panic, emotional distress, physical activity, or congestion.



[**Severe symptoms of asthma were more noticeable than other features of asthma**](#)

People tend to notice changes in their body when they are different from what people think is “normal” for their body. As a result, caregivers and children often did not notice the chronic airway inflammation that doctors associated with asthma. Instead, they noticed acute symptoms, like suddenly having serious trouble breathing. Indeed, severe symptoms or “asthma attacks” were the most notable part of asthma for both caregivers and children.

[**Asthma was both physical and emotional**](#)

Emotions such as fear, excitement, anxiety, and panic could feel very similar to asthma symptoms of breathlessness. This similarity made it difficult to determine whether breathlessness was caused by emotions or by asthma. Many caregivers described emotions as triggers for asthma. Other caregivers described how feelings of breathlessness from asthma could cause anxiety or panic. The connections between emotions and asthma meant that caring for asthma often involved caring for emotions as well.

The difference between how caregivers and healthcare providers understand asthma may lead to recommendations by healthcare providers that do not match caregiver practices.



5. Healthcare providers, caregivers, and children can all have different views of what managing asthma can and should involve.

Healthcare Providers

Most doctors and other healthcare providers we interviewed thought of asthma care in terms of how well caregivers followed their medication plans or “action plans.” Some healthcare providers noted social and environmental situations that worsened asthma, but in most cases, they did not focus on these situations. In general, doctors and other healthcare providers did not recognize the difficulty of caring for asthma while struggling with poverty.

Caregivers

Caregivers described asthma management practices that went beyond the medications and asthma plans. Caregivers appeared to develop their own practices partly in response to difficulties they faced accessing medical care.



For example, caregivers reported:

- Monitoring for symptoms

Caregivers closely watched and listened to children for symptoms.

- Managing emotions

Caregivers calmed their child during an asthma attack and tried to tell breathlessness apart from emotions like panic, or caring for children's emotional needs.

- Controlling the home environment

Caregivers controlled the home environment by cleaning, managing the temperature, filtering or purifying air, and trying to control others' smoking habits.

- Controlling the child's activity

Some caregivers restricted activity to avoid triggering asthma, and some caregivers encouraged physical activity to build lung capacity.

- Managing symptoms

Caregivers gave their children quick relief or rescue medication. Some caregivers did this when their child was having breathing problems. However, other caregivers gave it every day, thinking that it would prevent asthma in the future. They also used home remedies such as hot sauce, teas and other drinks, steam, and peppers.

However, the asthma management practices caregivers engaged in depended on their income. Caregivers with higher incomes were more easily able to connect themselves to healthcare providers and resources.

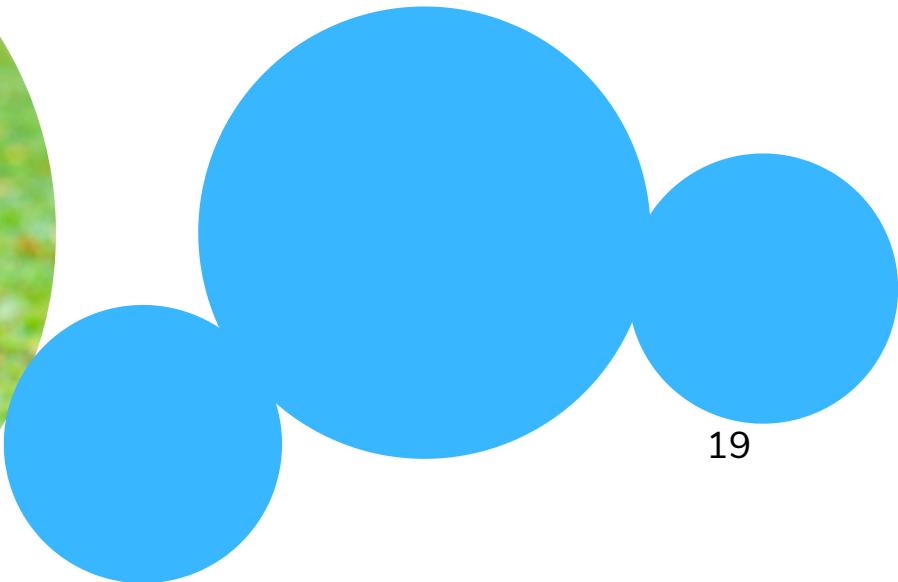
For example, they asked doctors for referrals to specialists, communicated complex health information between doctors, and researched medical treatments. Caregivers with lower incomes, who were more likely to be Black, reported more difficulties in trying to connect themselves to healthcare.

Children

Children often had information about asthma that their caregivers did not have, mostly about experiences of asthma at school or on sports teams.

Nevertheless, children's asthma management practices shared some similarities with those of their caregivers. These similarities included managing emotions and limiting physical activity. However, unlike caregivers, few children described managing their environments. In general, caregivers seemed to focus more on preventing asthma symptoms than children did. Children focused more on managing their asthma symptoms.

Many children's management practices were based on strategies that they learned from siblings, friends, healthcare providers, coaches, and caregivers. However, children also developed their own asthma management practices.



6. Children were central to asthma management.

Efforts to reduce asthma exacerbations among children often focus on their caregivers or their healthcare providers. However, asthma happens in children's bodies, not their caregivers' bodies or their providers' bodies. As a result, children do a lot of work to manage their own asthma.

Common self-management activities that children in our study reported doing included:

- Detecting and identifying symptoms of asthma
- Deciding when to tell an adult about their symptoms, ask for help, or see the school nurse
- Deciding when to slow down or take a break
- Deciding when to use a quick relief or rescue inhaler
- Remembering to bring asthma medications when they left the house
- Remembering to take daily controller medications
- Avoiding triggers
- Using their controller or quick relief medications
- Using alternative strategies for relieving symptoms (for example, resting, calming, drinking water, stretching, breathing slowly)
- Using alternative strategies for preventing asthma (for example, reducing activity)

Caregivers and healthcare providers seldom recognized children's asthma management practices.

Caregivers, healthcare providers, and even children could overlook, minimize, dismiss, or under-value the importance of children's self-management work. Most providers focused on directing caregivers in asthma management. In addition, providers seldom mentioned how children could take part in their own self-management practices.

Children reported various levels of interaction with doctors and other healthcare providers.

Some older children indicated that they took a main role in discussing asthma management with physicians. Other children could find physicians intimidating. They preferred their caregiver to communicate with physicians on their behalf, and then to translate physician messages back to them. This could be because providers are addressing caregivers more often than children.

7. Children's asthma management strategies were often shaped by challenges outside of their control.

Children developed strategies to manage their asthma in response to challenges they faced in their lives. For children, these challenges included school policies, feelings about medication, and difficulties navigating certain spaces in their lives.

School policies shaped children's access to inhalers

School policies often prohibited children from carrying their inhalers with them. They also required a school nurse to hold medications. When children's asthma was triggered while playing after school, they could not access their inhaler because the school nurse was no longer in the building.

This policy affected younger children more, because older children were sometimes allowed to carry their medication if they had a doctor's note. However, some children would hide their inhalers in their pockets and use it secretly if they started having breathing problems.



Children felt that their inhalers were important but also stressful

Inhalers featured heavily in children's drawings and in their interviews. They recognized how important it was for relieving breathing problems caused by asthma. However, keeping track of their inhaler was challenging and stressful for children, because it could be lost, forgotten, or misplaced. Even if children could find their inhaler, it could be empty or expired. Children tried to make it a habit to remember their inhaler so that they didn't experience negative consequences of not having one on hand.

The distance between children and their inhaler also created stress for children

Children often felt stress because they could get breathless walking from the playground or gym where they first felt asthma symptoms to the teacher, nurse, or locker room where their inhaler was kept.

Children used water for diagnosing asthma, intervening in asthma symptoms, or as part of a preventing asthma

For children, the advantage of water over inhalers was that water was easy to access. Water fountains were available in a gym class or on the playground. Friends' homes had water, and when medication ran out, water was available in the children's homes.



Next Steps

What are we doing with these findings?

Findings from this report have informed:

- Presentations to asthma care providers
- The development of two large-scale surveys on caregiver risk perception and asthma management
- A number of articles published in scientific journals. For more information on these articles, please see the appendix.
- Presentations at a number of academic conferences

This project is ongoing. We are currently gathering responses from two nationwide surveys about how caregivers' thoughts and feelings about their child's asthma affect their asthma management practices. We are also examining how issues like housing problems, communication with providers, and other structural issues affect asthma management practices.

Findings from this report and the nationwide surveys will help us develop an intervention to support caregivers, healthcare providers, and children in managing childhood asthma.

If you would like to learn more about this study, please contact Dr. Erika Waters at waterse@wustl.edu.



How can caregivers help with their child's asthma?

Check with your doctor about:

- An asthma control test to check if your child's symptoms might be a concern
- An up-to-date asthma action plan for your child
- Whether your child needs controller medication, if they're on the right dose and taking it the right number of times a day
- Whether your child is using the correct inhaler technique
- If you can get spacers for inhalers
- If your child can see a lung specialist

Talk to your child about how they are experiencing and managing asthma. Ask them how you can support them with the tasks they are already doing. Children do a lot of work to manage their asthma, and it's important to recognize their efforts. Talk with your family about ways to incorporate asthma management into daily routines as well.

Connect with your school nurse for support with asthma management.

Find free resources and community support through the Asthma and Allergy Foundation of America (www.aafa.org).

How can providers use the information in this report?

Providers are in a unique position to support caregivers and their children in managing asthma. Strategies include:

- Acknowledging that caregivers may be living in challenging situations with financial pressures, housing difficulties, complex family situations, and residential segregation. Providers could work with social workers to assist with unmet needs. Better resourced primary care clinics could offer advocacy interventions such as medico-legal partnerships or partnerships with other organizations that aid families.
- Proactively seeking information about the child's asthma and remaining mindful that caregivers may not prioritize non-acute asthma checks when bringing their child for other issues. Asking specific questions and continuing to follow national guidelines for routine assessment of asthma control may help identify needs that families themselves do not recognize.
- Acknowledging caregivers' work to manage asthma even when it falls outside of conventional medical practices. Providers can ask about caregivers' practices of identifying when their child is having asthma trouble, acknowledge caregiver expertise in their child's asthma, and support caregivers' efforts. This process could increase trust and engage caregivers in the process of creating asthma care plans.
- Recognizing the need to support and educate multiple caregivers. For example, a printed visit summary with detailed asthma care instructions may help communication across multiple households.
- Affirming the individuality, ambiguity, and uncertainty of asthma. These conversations can start at or before diagnosis, so caregivers are prepared for uncertainty. Providers can also recognize and explain differences between caregiver or patient experience and the biomedical model of asthma.

- Validating children's role and work in their own asthma management by eliciting and having meaningful interactions with children during clinic visits. Providers can ask children questions like: "What are the things you do to manage your asthma? What do those things do for you?" and then validate their efforts by saying, "You've worked out some good strategies. Would it help to talk through some more strategies?" to learn more about children's work.
- Supporting further research on children's participation and inclusion in their healthcare. More research on children's experiences of their health and healthcare can support efforts to illustrate how children themselves understand their bodies and their healthcare. Research with children can create greater understanding between physicians, caregivers, and other stakeholders about children's roles in their own healthcare.
- Recognizing that questions asked to assess asthma control, such as those that assess symptoms and albuterol use, may be interpreted by caregivers and children differently than healthcare providers intend.



What policy changes might improve asthma care for children?

Many environmental conditions that contribute to asthma disparities are largely unmodifiable through individual practices—particularly in circumstances of economic constraint—and require collective structural change. This means that it is critical for providers, caregivers, and other stakeholders to advocate for local and national policy change directed at the structural determinants of health that include:

- Equity based housing, pollution, or public transit policy that helps improve the living conditions and accessibility of healthcare resources for marginalized populations
- Enhanced national guidelines that recognize children's roles in their asthma management and provide guidance on how to include children as participants in their asthma management
- Provider training on how to include children as participants in their asthma management
- School policies that allow children to carry their own inhaler or ensure children's access to their inhaler
- Advocacy for insurance policies to increase access to multiple inhalers to reduce children's mental load of having to carry one inhaler around to multiple places
- Increasing the availability of generic inhalers so that more caregivers have an affordable medication option

Authors and Acknowledgements

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If you would like to learn more about this study, please contact Dr. Erika Waters at waterse@wustl.edu. You can learn more at <https://waterslab.wustl.edu/research/asthma/>

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Appendix - Published Works

1. Shepperd et al. Caregivers' use of surrogate social comparisons to draw conclusions about the status of their child's asthma. In development.
 2. Spray et al. How do embodied experiences of asthma influence caregiver conceptual models? In development.
 3. Ruiz et al. Towards emplaced understandings of risk: How caregivers of children with asthma identify and manage asthma-related risk across different places. In development.
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